Women With Disabilities Australia (WWDA)



Submission to the Senate Community Affairs References Committee

Inquiry into Planning Options and Services for People Ageing with a Disability.

May 2010

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1. About Women With Disabilities Australia (WWDA)

Women With Disabilities Australia (WWDA) is the peak organisation for women with all types of disabilities in Australia. WWDA is run by women with disabilities, for women with disabilities. It is the only organisation of its kind in Australia and one of only a very small number internationally in that it operates as a national disability organisation; a national women's organisation; and a national human rights organisation. WWDA represents more than 2 million disabled women in Australia. WWDA is inclusive and does not discriminate against any disability. The aim of WWDA is to be a national voice for the needs and rights of women with disabilities and a national force to improve the lives and life chances of women with disabilities. WWDA addresses disability within a social model, which identifies the barriers and restrictions facing women with disabilities as the focus for reform.

WWDA is committed to promoting and advancing the human rights and fundamental freedoms of women with disabilities. Our work is grounded in a rights based framework which links gender and disability issues to a full range of civil, political, economic, social and cultural rights. This rights based approach recognises that equal treatment, equal opportunity, and non-discrimination provide for inclusive opportunities for women and girls with disabilities in society. It also seeks to create greater awareness among governments and other relevant institutions of their obligations to fulfill, respect, protect and promote human rights and to support and empower women with disabilities, both individually and collectively, to claim their rights. A rights based approach also demonstrates, in a practical way, our organisation's commitment to the implementation of the core international human rights treaties ratified by the Australia Government, in particular the *Convention on the Rights of Persons with Disabilities* (CRPD), and the *Convention on the Elimination of Discrimination Against Women* (CEDAW).

More information about WWDA can be found at the organisation's extensive website at: www.wwda.org.au

2. Background

For some years, it has been a concern of WWDA that scant policy attention has been paid to developing supports for people with disabilities, especially women, as they age. This Submission forms WWDA's initial response to the Senate Community Affairs References Committee Inquiry, announced on November 25th 2009, into Planning Options and Services for People Ageing with a Disability. While this submission considers the situation of people ageing with long-term physical impairments, many of the recommendations are equally applicable for people with sensory or psychiatric disabilities.

3. The Australian Policy Context

Like their non-disabled peers, people with disabilities are surviving longer and ageing in larger numbers than ever before. Life expectancy has increased in Australia, as in other major developed nations, because of improved medical care and a better quality of life. Mortality is delayed by better living conditions, sanitation and

medicine (Oeppen & Vaupel, 2002, UN, 2002) and improvements in levels of education. Australian studies have shown an increase in age at death (McCallum 1997, Coory 2004, AIHW 2000). In addition the numbers of people reporting disability but whose disabilities are not the direct cause of death, have increased (Borowski & Hugo 1997, McCallum 1997, ABS 2003). The percentage of Australians aged 65 and over is expected to increase from 12% of the population in 1997, to 18% in 2021, and 27% in 2051 (Ministerial Reference Group a & b, ABS, 2004). However, there is insufficient parallel information about indigenous populations (ABS, 2004).

It has been shown that there is a direct relationship between ageing and acquired impairment (ABS 1999, AIHW 2003, Giles, Cameron & Crotty 2003), with osteoarthritis being the primary cause of disability in the elderly (March & Bagga 2004). Osteoporosis disproportionately affects females and is the cause of fractures in 30%-50% of older women (Seeman & Eisman 2004), whereas the incidence for men is a much lower 15%-30%.

Although there is an economically based assumption that older people are a drain on the nation's resources (Commonwealth 2003), ageing persons do contribute significantly to their communities. In addition there is debate about the level of their health care costs (Coory 2004). Expenditure on health, as a proportion of a nation's Gross Domestic Product, by countries belonging to the Organisation for Economic Co-operation and Development (OECD) has not been found to relate to ageing of the population (Coory 2004). Moreover, ageing of the Australian population has been shown as not associated with increased use of hospital beds (Gray et al 2004). In fact, older people generate investment monies. They may share wealth with younger generations; they do voluntary work in charities, and care for grandchildren and ill relatives (ABS 2004, Warburton 2004). Their contributions, rights and responsibilities must be recognised. In fact the United Nations International Plan of Action on Ageing states that nations must enable:

"Empowerment of older persons to fully and effectively participate in the economic, social and political lives of their societies including income generation and voluntary work (UN 2002, 12.c)".

Ageing is a process of life complicated by individual emotional reactions to the inevitable approach of its end. Ageing also means that one's ability to increase and maintain physical reserve is diminished (Mosqueda 2004). There are a number of theoretical approaches which influence the planning of service options for people entering this stage of life. These include biomedical, social and citizenship, economic, ecological, and successful ageing paradigms.

Importantly, the majority of these planning paradigms completely ignore the situation of people ageing with disabilities.

In the 2003 Survey of Disability, Ageing and Carers, disability was claimed by 3,958,300 people living in Australia (ABS, 2004). This constituted approximately 20% of the Australian population at that time. The Australian Bureau of Statistics defines a person as having disability if they have one or more "limitations,"

restrictions or impairments which has lasted, or is likely to last, for at least six months and restricts everyday activity" (ABS 2008). This definition is based on the International Classification of Impairments, Disabilities and Health as published and developed by the World Health Organisation (Geneva, 1980).

In contrast, the UN Convention on the Rights of Persons with Disabilities (CRPD) endorses a social model of disability and acknowledges changing societal perceptions. It recognises that:

"...disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society" (CRPD, Preamble clause [e]).

The rate of disability was noted to increase with age (ABS, 2003, AIHW, 2000).

WWDA is concerned that it is unclear which government will fund and manage the care of people ageing with long-term disabilities. The Health and National Hospitals' Agreement of April 2010 gave the Commonwealth full funding and policy responsibility for aged care. The reform will involve a transfer to the Commonwealth of current resourcing for aged care services from the Home and Community Care (HACC) program (except in Victoria). It is proposed that this change will take effect from 30 June 2011. Within Victoria, the existing arrangements will remain in place until otherwise determined. An anomaly exists in that packaged community and residential aged care, and specialist disability services remain under the National Disability Agreement. There is confusion amongst people with disabilities as to whether they will still be able to access disability services, day centres or community based disability worker support for example, once they reach the age of 65, or whether they will be transferred to the care of strangers in aged care systems.

Several key issues must be addressed to enable positive ageing of people with long-term disabilities as well as those ageing with age associated impairments.

4. Key issues

4.1 Positive Ageing versus Successful Ageing

WWDA uses a positive ageing perspective. The term 'positive ageing' has a broader meaning than 'successful ageing'. The latter refers mainly to the well elderly who have little loss of abilities (Rowe & Kahn 1987). Positive ageing indicates a reciprocal relationship and respect between the individual and society and is summarised in the UN Madrid Plan:

"It is essential to recognise the ability of older persons to contribute to society by taking the lead not only in their own betterment but in that of society as a whole" (UN 2002).

People ageing with disabilities contribute greatly to the communities around them. They have life goals and value what they have achieved as partners, parents, friends, workers and volunteers. The majority now care for their aged partners, adult children, aged parents, aged friends and grandchildren.

Positive ageing or ageing with quality of life has many facets. Positive ageing is dependent on mental health and well-being (Browning et al 2005). Well-being is in turn dependent on the quality of life. The dimensions of the quality of life may include personal autonomy, cultural and social integration, purposeful activity, quality of environment, socio-economic status, physical and mental wellbeing, and expressed satisfaction (Hughes 1990). People with disabilities are particularly concerned about maintaining control of their lives and pursuing their chosen social roles and goals.

4.2 Ageing versus ageing with long-term disability

People with disabilities have to cope with additional issues as well as those associated with ageing. They need to be differentiated from people with age-related health conditions (Crewe 1990, Putnam 2002, Mosqueda 2004). Sometimes people with disabilities find that their impairments progress and that their ageing is accelerated, so that age-related conditions manifest well before they reach the chronological age at which such symptoms might be expected. These people need assessment and appropriate services at this earlier time, and re-assessment again when ageing.

Progression of a person's impairment is sometimes mistaken for ageing. Often as people with disabilities enter into their third or fourth decade of life, they seek help because they notice a deterioration in their ability to cope with core activities. Core activity limitation is determined by the individual's need for assistance or equipment to undertake tasks involved in communication, mobility or self care (ABS 2003). Limitations are described at four levels which range from mild to profound. A severe or profound core activity restriction, meaning the person always needs help with one or more core activities, was reported by 1,244,500 persons (6.3% of the Australian population, and 31% of people with impairment or disabling main conditions (ABS, 2003)). The rate of core activity restriction increases with age.

Impairment progression is not the same process as ageing and should be treated differently and at the time it becomes evident in individuals' lives (Thompson 2004). Impairment progression is used to describe symptoms such as new pain, fatigue, weakness and bony problems, resulting in deterioration in the individual's ability to continue as high a level of activity as before. It occurs in a wide variety of impairment groups and has been most clearly reported by medical and scientific researchers as associated with polio, spinal cord injury and cerebral palsy (Bruno 1991,2002, Treischmann 1986, 1992, Gerhart, 1993, and Gerhart, 2001 cited in Mosqueda, 2004)

4.3 Factors affecting women with disabilities.

As a component of moving into the ageing process, all women have to cope with menopause whether it occurs naturally or by surgical intervention. Some will also have to live with some level of osteoporosis. Women with impairments have particular vulnerabilities which are often ignored.

There is no Australian research on osteoporosis in women with long-term disabilities. A study conducted in the USA showed the risk factors for women who are mobility impaired are greater than for their non-impaired peers (Haziza et al 2007). The records of 164 patients of a post-polio clinic were reviewed to determine the frequency of osteoporosis at the hip and lumbar spine in a post-polio clinic population. Osteoporosis occurred commonly at the hip. Hip bone density was associated with muscle strength in the same lower leg (Haziza 2007). Another USA study showed that similar risks were found in males and females in the spinal cord injury population (Garland et al 1992).

There is no Australian research on menopause experienced by women with disabilities. American women who had a history of polio were surveyed on their health status, post-polio *sequelae* and menopause transition (Kalpakjian 2004). A total of 1283 men and women completed a questionnaire, with the majority (909 females) completing an extra module regarding menopause. Ninety-five percent of people in the study were of Caucasian background. The average age of respondents was 63.5 years, so most were post-menopausal. This project was the first of its kind into the interaction of physical impairment and menopause (Kalpakjian 2004). There were interesting findings. The severity of post-polio sequelae related significantly to the severity of menopause symptoms. In turn severity of menopause symptoms was related to lesser emotional well being. Post menopausal women reported higher levels of stress than their male peers. In addition, women with disabilities used Hormone Replacement Therapy (HRT) at a higher rate than women in the general community. The use of HRT was not associated with better physical functioning or emotional wellbeing. Hysterectomy rates for women with disabilities were significantly higher than non-disabled women.

Women with disabilities throughout Australia bear a disproportionate burden of poverty and are recognised as amongst the poorest of all groups in society (WWDA 2006, Saunders 2006). In Australia, twenty-one per cent (21%) of men with disabilities are in full time employment compared to nine percent (9%) of women with disabilities. In any type of employment women with disabilities are more likely to be in low paid, part time, short term casual jobs (WWDA 2004). These factors mean women with disabilities have less chance to accumulate resources to cope with non-optional expenses, yet these expenses increase more steeply as they age compared to their male peers and to non-disabled women. Thus employment history will have a profound impact on the poverty levels of women with disabilities as they age.

4.4 Ageing with long-term impairments

WWDA believes that people ageing with long-term impairments have issues which are not recognised by planners and service providers. These include not understanding the disability experience, confusion of impairment progression and the ageing condition, gender and disability discrimination issues affecting women with disabilities, and lack of information about how people with disabilities perceive ageing.

Although, longevity has increased for both impaired and non-impaired populations in the USA (Crewe, 1990, Putnam, 2002, Torres-Gil & Putnam, 2004) and Australia (ABS, 2004), not enough is known about the ageing process for those with long-term impairments (Crewe 1991, Cooper 1998, Putnam 2002). In this submission, a long-term impairment means one which has existed for a decade or more. Already, ageing with psychiatric impairment is becoming a focus of new research as those affected by major long-term psychiatric disorders join the ranks of the elderly (Harvey et al 2006).

Ageing is an extra process people with disabilities have to deal with. The effect of having coped with some level of impairment through life stages means that people with disabilities start their ageing from a lower base-line point than their non-disabled peers. People with disabilities face the same issues of age-related impairments as their families, friends and neighbours, but these are superimposed over their existing impairments. Many people with disabilities have had lesser opportunity for full development of physical, intellectual or psychological potential before entering ageing (Mosqueda 2004). They may also have had less opportunity to build financial resources from employment and have less ability to financially cope with expenses associated with later life (Mosqueda 2004).

There is insufficient information about the numbers of people ageing with long-term disabilities. Available statistical data does not give clear information about the numbers of people ageing who have lived many decades with impairments. Sometimes people living with long-term impairments have chosen not to declare their conditions to statistical surveys.

Available information shows that many people have multiple disabilities. Analysis of data carried out by the Australian Institute of Health and Welfare into Disability and Ageing, shows that early onset of disability occurring before the age of 18 years, is reported by about 10% (112,500) of the total population with disability (AIHW 2000:103). For those with severe profound core activity restriction, 11% (30,200) had acquired this level of disability before age 18. However the majority (63.3%) of those with early onset of disability are people who have an intellectual disability as their main disabling condition. Physical (8.3%) and psychiatric (10.6%) conditions were least like to have occurred before the age of 18.

Data is not yet available which discriminates between people with long-term physical impairments who are ageing and people whose impairments are related to ageing alone. There are some indicators that the former cohort is growing. The increased need for assistance in the populations aged 45-64, and those aged 65 and over, has significant implications for family and informal carers, service providers, and people living with impairments as well as coping with ageing life stages.

4.5 Citizenship

The experience of living with disability is relevant to how ageing is handled. People with disabilities have had to develop strategies to cope with stigma and discrimination. Too many have had to struggle to achieve a measure of citizenship. Full exercise of citizenship may be challenged in the elderly (Carney 1997) and further challenged for those who have been rendered vulnerable by their disabilities earlier in their lives.

Consideration of citizenship is crucial in understanding the particular situation of people ageing with long-term disabilities. Citizenship means participation in decisions which determine our society, and exercising the right to control over one's circumstances. Civil and political aspects of citizenship refer to the capacity to vote, to have access to education, health care and other services, and to receive just treatment under the law. Civil citizenship refers to the capacity to exercise the rights to contracts, education and other opportunities of civil society.

The aspect of citizenship which crucially affects people with impairments is in the social roles attributed to them. Prejudice still exists. People with impairments and disability continue to be perceived as on the boundary of society. Prejudicial attitudes and treatment also come, in part, from all people with disabilities being ascribed the characteristic of dependence and the role of burden on the nation's welfare system (Newell & Goggin 2005). Such negative and often misinformed attitudes come in part from the need for some people with disabilities to have some support from the state, in the form of state-funded care programs, or full or partial social security payments to offset a permanent or temporary inability to engage in full-time or part-time work.

Citizenship issues are relevant to people with disabilities as they age. Three facets of citizenship applicable to older people are: income security including housing; personal rights and equality of access to full citizenship rights (Carney1997). Income security is related to whether full superannuation schemes were available during the individual's working life. The age of the individual at the time of retirement is relevant when retirement is forced at an early age because of impairment or loss of employment. Income may also be affected by changes in tax levies, costs of private health insurance and general economic swings.

There are systems for helping financially challenged people to get aged and community care services but there are obvious inequities caused by "structural lag" in which mismatching Commonwealth and State/Territory funding and programs inevitably creating gaps (Pfeffer & Green 1997). These inequities result in poverty and poverty traps for recipients and for those deemed ineligible for assistance. There are interface barriers which

frustrate the ageing in place aspirations of people with disabilities (NDS 2009). Ageing people who do not have their own homes may become homeless. This can occur when the person has a temporary or permanent deterioration of their condition and needs community based care. There are waiting lists for any form of community care. The consequence is both an accommodation and a need-for-care crisis occur.

People ageing with disabilities continue to value having control over their lives. Many are afraid that a life crisis might mean they lose control over their choices of care, accommodation or life goals. Ageism attitudes from service providers occurs when services take over elderly clients' choices (Cohen 1988). Personal rights such as respect and dignity may be threatened by the way a request for help is interpreted.

Ageing may bring additional impairments to persons with long-term disabilities, forcing such people to develop new ways of adapting their lives. They can face emotional turmoil and may need skilled help from peers with disabilities, or professionals, to assist in developing coping strategies. Coping strategies include finding an element of personal control by focussing on the positive aspects of a traumatic experience, or finding some meaning in the event (Thompson 1993). The more substantial the impairment, the more important the individual's social and material environment will become to the realisation, or otherwise, of personal goals. People with disabilities have to marshal their own resources and, when necessary, seek external sources of help.

4.6 Lack of informed advisors and services

For people ageing with disabilities there are very few health professionals who can advise them and even less access to crisis services. They need services where personnel are trained in disability and ageing issues (Bigby, Fyffe and McCubbery 2005). Very few clinics in Australia are able to work with people who need management of their primary impairments as well as aged care assessment. These clinics are usually for people with intellectual disabilities.

Although the last Australian polio epidemic was 1954-56, survivors live on. There may have been 70,000 Australians paralysed by polio between 1936 and 1961 (Jones 1991). Despite the significant numbers, there are only two polio clinics in Australia, one in Victoria and one in Western Australia. The majority of their clients are ageing. Staffing limitations mean they are not able to provide full assessment of ageing concerns, nor can they supply ongoing care for polio related impairment.

Anecdotal reports indicate that if people with impairments do engage with the aged care or acute hospital systems they are unlikely to encounter treating professionals with knowledge, and therefore empathy, concerning their primary impairment (Deane 2009). Health care workers do not comprehend the complicated adaptive strategies which their long-term disabled clients have had to develop in order to get on with their lives.

Leaving the population of people ageing with impairment unexamined by gerontologists and associated professionals is dangerous because of the risk of high incidence of untreated secondary conditions, unnecessary dependency and unnecessary polypharmacy (Annison et al 1996). It is arguable that professional neglect of the field of ageing for people with physical impairments is due to a trained mindset whereby health care professionals see such patients as chronically biologically dysfunctional (Temby & Cooper 1996, Barnes 2003).

4.7 Disability service providers need aged care skills

People with disabilities can also acquire age-related health conditions and need appropriate assessment by geriatric medical services and assistance from skilled service providers. It would be useful to trial a program similar to the British Expert Patient Program (Barlow et al 2000, Shaw & Baker 2004). This would enable the disabled patient to share their knowledge of their impairments and gain new information from their health professional to cope with ageing issues.

Ageing in place is important. Great distress is caused by the arbitrary cut-off of disability services at age 65 with a consequent transfer to aged care. Disability service providers are more influenced by consumer expectations and have some understanding of the social model of disability, whereas aged care models are still more prescriptive (Putnam 2002).

5. Recommendations

People with disabilities have contributed to Australia and their various communities. They have extensive knowledge in managing their respective conditions but need more advice and help while journeying through ageing. Australia has ratified the UN Convention on the Rights of Persons with Disabilities and its Optional Protocol, and has thus committed the nation to protect the rights of those with disabilities regardless of age.

Women With Disabilities Australia makes the following recommendations to assist people with disabilities, policy makers and service providers to become informed about the issues and to develop appropriate interventions:

- 5.1 Positive ageing, with quality of life performance indicators, must be included in the objectives of every service provider involved with people ageing with long-term disabilities;
- 5.2 People with disabilities must be enabled to age in place by removal of the barriers identified by National Disability Services (2009);

- 5.3 Where necessary, people with substantial disabilities must be assisted to stay at home, with increased support funded from a specific aged care package to meet expenses not covered by their current Individual Support Package or other support funding;
- 5.4 The National Women's Health Policy must incorporate longitudinal research on women with disabilities particularly in relation to menopause and osteoporosis;
- 5.5 The Royal Australia College of General Practitioners, the Royal Australasian College of Physicians, the Australian and New Zealand Society for Geriatric Medicine, the Australasian Faculty of Rehabilitation Medicine, the Australian College of Nursing, the Australian Physiotherapy Association, the Australian Association of Social Workers and other health professional organisations must develop training modules about the issues confronting people ageing with any form of long-term disability;
- 5.6 These colleges and associations must develop assessment protocols which recognize and take into account the experience of people with disabilities and work with their clients to enable them to:
 - i. maintain their skills
 - ii. maintain their independence
 - iii. be educated in ways of caring for their health conditions
- 5.7 Clinics must develop to deal with the necessity of providing impairment management advice and address issues experienced by people with disabilities as well as providing assistance with ageing processes;
- 5.8 In recognition of the skills of self management developed by people with disabilities to cope with long-term impairments, medical practitioners should trial the British Expert Patient Program;
- 5.9 Medical and health professional organisations work must with National Disability Services to develop the aged care skills needed to assist clients within disability services;
- 5.10 Longitudinal research must be undertaken to look at the effectiveness of service providers' aged care programs and develop innovations in care options.

6. Conclusion

The information in this submission is garnered from the sparse research and statistical data which available on the topic, supplemented by anecdotal information provided by seniors who are women with long-term disabilities. A further limiting factor is that almost all of the data and research on ageing with disabilities has been undertaken without gender disaggregation, as if the experience of disability and the experience of ageing are identical for both women and men. In the non-disabled population this assumption is rarely made. Therefore in this submission it has generally not been possible to nominate specific effects for women with disabilities. Yet, given that they experience greater marginalization than their male peers in most areas of their lives, and at most stages of their lives, it is likely that women with disabilities will need pro-active programs to ensure that the inequities experienced in earlier life are not perpetuated and exacerbated in older age.

As in many other areas of disability studies there is an urgent for research and the collection of data. Data must be routinely disaggregated by disability and gender, with efforts made to identify other differentiating factors such as multicultural background; Aboriginal or Torres Strait Islander descent; lifestyle choices and rural, remote place of living. Statistical information must be made publicly and freely available for non-government research purposes.

The societal and policy structures which have shaped the life-long experiences of women with disabilities mean that they are likely to experience greater poverty in old age and for longer periods of time than their male counterparts. In particular the portability of services over State/Territory boundaries must be addressed for women with disabilities as they age. Similarly the transition from disability services to aged care services must be eliminated or made seamless.

Women with disabilities must also be involved in planning and on advisory groups formed to develop policies and programs that will improve the ageing experience for this significant and growing group of the population.

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